



Medication Management and the Role of the Care Partner

In April 2020 the World Parkinson Coalition® held the first in its Care Partner Virtual Panel Webinar Series. Julie Carter, RN, MN, ANP and Professor Emeritus at Oregon Health & Science University moderated the webinar on Medication Management and the Role of the Care Partner, a critical part of daily life with PD and the ability to effectively address symptoms and other Parkinson’s challenges collaboratively. She began by reminding viewers that research tells us that couples and partners cope better when they approach Parkinson’s disease (PD) with a shared outlook – that they are “in this together.”¹ During this virtual panel, four experts offered advice for care partners related to beginning or maintaining a role in this aspect of care.

The Movement Disorder Specialist

Dr. Sneha Mantri, MD, MS, *Duke University Movement Disorders Center*

Medications can’t stop or reverse PD progression, but they are very good at treating specific symptoms like slowness, tremor and depression. It is important for both the person with Parkinson’s (PwP) and their care partner to have clarity about the applicable terminology, the medications the patient is using and are available to them, and what symptoms the medications can address.

Here are some of the important things to keep in mind when talking with your clinician about your PwP’s personalized medication regimen:

- There is a wide variety of medications that can address motor symptoms (tremor, balance, gait), as well as non-motor symptoms (mood, memory, constipation, urinary problems, etc.).
- Clinicians use words like ON and OFF to describe when the medication is or is not working. When a PwP is ON, they might be able to speak and get around similarly to how they used to before Parkinson’s. As the medications wear OFF, their PD symptoms may return. It’s important to keep track of how much ON time a PwP gets from each dose of medication, and how gradually or abruptly they transition to OFF.
- The time to consider changing, increasing or adding new medications to a Parkinson’s treatment plan is when the PwP is experiencing functional limitations or a decreased quality of life – e.g., an increase in “off time.”
- Accurate information and honest reporting is the key to creating an effective treatment plan, and care partners play a critical role in communicating with the clinician about symptoms and general wellness.
- Treatments and information regarding PD is constantly changing, so it is important for a PD specialist to be involved in your PwP’s team.

The Parkinson’s Educator

Lisa Mann, RN, BSN, MA, *OHSU Parkinson Center*

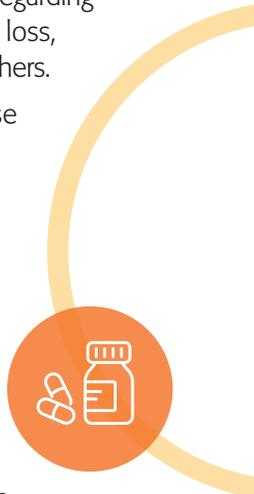
The care partner can make a huge difference in a PwP’s treatment plan by engaging effectively in the administration of medications. Because PD is progressive, medications will need to change over time, making communication key to ensuring both the PwP and his or her care partner is up to date on administration. This involvement can make a world of difference to not only day-to-day safety and quality of life, but also the comfort and effectiveness of a hospital visit or stay.

Tips for Communicating About Medication:

- Both PwPs and care partners need to understand the importance of the care partner’s role in medication administration, especially when considering communication with physicians both during regular appointments and in potential emergency situations.
- There are many natural reactions and emotions involved in a care partner taking on more responsibility regarding medication administration – fear, a sense of loss, resistance to becoming more dependent on others.
- Effective communication will be easier if those involved can keep communication regarding medications straightforward, honest, and direct.
- There are many tools available to help record and update medication information and assist with administration (see Tools and Resources We Mentioned).

If PD symptoms have worsened, be prepared to answer these questions when contacting your medical provider for assistance:

- WHAT** is the problem? **WHERE** on the body?
- WHEN** did it start, how often does it occur, and for how long?
- HOW** do certain things impact it, ESPECIALLY PD meds?
- WHAT** else was new or changed about the time the problem started?



¹ *Benefits of a Self-Management Program for the Couple Living With Parkinson’s Disease: A Pilot Study*
<https://journals.sagepub.com/doi/full/10.1177/0733464820918136>

The Person with Parkinson's

Kat Hill, RN, CNM, NP, *Diagnosed in 2015 at age 48*

Communication is the most important tool you have as a couple or PwP/care partner team, especially when it comes to the hard things like Parkinson's progression and managing medications. Here are some words of wisdom about medication management and maintaining healthy communication amidst the relationship challenges PD presents:

- Remember that medication is just one tool of many that can optimize well-being.
- It's important for care partners to understand that most PwPs want to maintain control and independence in their lives, which often shows up as resistance to accepting help.
- Don't try to solve conflicts and issues in the heat of the moment.
- Build an expectation and comfort level with frank honesty and difficult conversations.
- Be aware of the role your ego plays in accepting or offering advice or help, and consider that learning to accept help can be a beautiful lesson found within your PD experience.
- PwPs know their bodies better than anyone, but it's important they be honest with themselves about how they feel physically and emotionally.
- It's important for care partners to encourage and hold PwPs accountable to established communication expectations.



It's valuable for both the PwP and care partner to discuss and prepare for physician appointments ahead of time. Both should be on the same page about symptoms and progression, and be a united front.

The Care Partner

Ken Hill, MS

Peace of mind is important for care partners and PwPs alike, and knowing and understanding medication regimens is key to achieving and maintaining it. As a care partner who recently became involved in this aspect of Kat's care, Ken offered some advice for care partners:

- We are our PwP's back-ups, but we need to find our own back-ups, as well.
- Freely utilize smartphones and other tools – calendars, reminders, apps, logs, booklets, etc.
- Learn to be okay with the reality that the process is and will be difficult, and be kind to yourself.
- Acknowledge that both parties may have a resistance to talking frankly about when help is needed. Choose your timing carefully and set realistic expectations for the conversation.
- Following the consistent advice to have an "emergency backup plan" may be a successful way to start a conversation around medication management.
- Effective communication doesn't typically result from an expectation that one or both parties has to "fix" something, or everything.
- When in doubt, reach out to other care partners for advice and support.



"The most important tool we have as a team is communication ...over the years, Ken and I have developed a good dance and a good way of communicating even the hard things."

– Kat Hill

Watch the Webinar

www.worldpdcoalition.org/carepartner

Tools and Resources Mentioned by the Panelists:

Parkinson's Checklists, Logs and Other Tools – Davis Phinney Foundation for Parkinson's:
<https://www.davisphinneyfoundation.org/resources/worksheets-and-downloads/>

Aware in Care Kit – The Parkinson's Foundation:
<https://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/Patient-Safety-Kit>

Symptom Diary & Medication Log – The Parkinson's Foundation
<https://www.parkinson.org/Living-with-Parkinsons/For-Caregivers/Home-Care/Medications-and-General-Health>

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